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AUTHOR Rogers, Joy J.; Peelle, Judith
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ABSTRACT

One way of monitoring the effects of ethical and legal issues concerning severely handicapped students is establishing an additional level of review in the public schools. The Human Rights Committee (HRC) in one district, composed of multidisciplinary professional and community staff, has reviewed 56 individual behavior management programs considered too restrictive for approval by staff conference alone. The increase in number of behavior programs involving restraints and aversives after the HRC's establishment may be explained by the admission of more severely behavior disordered students in the public school setting and the provision for more in-depth discussion of treatments before they were instituted. (CL)

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ASSURING THE RIGHTS OF THE SEVERELY HANDICAPPED

Joy J. Rogers
Loyola University of Chicago
and
Judith Peelle
South Metropolitan Association
for Low Incidence Handicapped

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Litigation and legislation involving protections for the rights of handicapped students have made educators responsible for assuring the rights of handicapped children in specific, legally defined ways (Turnbulll and Turnbull, 1978). Staff of school programs serving children with severe handicaps, however, may have serious misgivings that the law does not go far enough in rights assurance for children with severe handicaps. While recognizing the general appropriateness of existing legal protections for most special education students, parents and educational professionals alike may face ethically complex decisions in completing educational plans for these children.

Such dilemmas appear to arise in three distinct types of situations. First, the nature of a particular child's behavior may be such that the continuance of the behavior would be life-threatening for the child, but all treatments except those with a significantly aversive component have been ineffective. Common examples include self-abuse and running away by children who lack sufficient cognitive skills to protect themselves in traffic. Second, the multiplicity or complexity of a child's problems may be so great that all courses of

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action carry significant risk to the child. For example, a child may be very seriously underweight and also prone to pica involving potentially toxic substances. Failure to deal with the pica risks the child's safety, however any treatment of the pica could further jeopardize an obviously already problematic feeding situation. Third, the status of a particular child as a ward of the court or in institutional residence seriously clouds the usual assumption that the parent or guardian giving consent for a treatment knows and loves the child and is inclined, therefore, to act in the child's best interests.

One mechanism for dealing with such concerns is the voluntary establishment, by the school program, of an additional level of review for such problematic situations. The Human Rights Committee(HRC) of the South Metropolitan Association for Low Incidence Handicapped(SMA) is an example of how one public school special education program approaches the problem. The HRC consists of 23 members of which 13 are voting and 10 are advisory. The advisory members are South Metropolitan Association staff members representing the various programs within the agency. Except for one SMA administrator, the voting members of the HRC are not staff members of the agency. They include educators, physicians, an attorney, representatives of state social service agencies, a university professor, parents of children enrolled in SMA programs, an SMA Executive Board member, and a former consumer of special education services who is also a representative of a related community agency. Although the committee has two major functions, the review of program-wide behavior management practices and the consideration of special cases, only the latter function is

relevant to the present discussion.

Throughout its three years of existence, the committee has reviewed a total of 56 individual behavior management programs. These programs contained elements considered too restrictive for the multidisciplinary staff conference alone to grant final approval. However, over that same time period, a total of 143 individual behavior management programs have been written for children served by SMA (Some children have more than one behavior management program because the programs are specific to the particular behavior.) Most of the children who require such individualized programming are students in SMA's Center for Adaptive Programming(CAP) which serves severely, profoundly, multiply handicapped, and autistic children. In order to preserve confidentiality, individual cases reviewed by the HRC are identified only by the child's first name. HRC review of an individual case does not require parental consent; however, the parents are notified of the meeting and have the option of attending. Regardless of HRC approval, all behavior management programs brought before the committee must have written parental consent prior to implementation. Also, regardless of HRC or parental consent, no program may be implemented which is contrary to SMA policy.

Initial staff fears were, obviously, that HRC review would place such severe restriction upon the use of aversive components that the program would be unable to train or even safely retain children with life-threatening behaviors. However, the data suggest quite a different picture.

Insert Table 1 about here

Note that the data from the 1979-80 academic year describe the provision of individual treatment programs before the creation of the HRC. It is immediately apparent that the number of behavior management programs produced altogether as well as the number of behavior management programs involving restraints and aversives increased rather than decreased after the creation of the HRC.

Interpretation of these data is problematic because none of the pre-existing legal safeguards had been removed. However, perusal of the particular behavior management programs written over the four year period described in Table 1 gives a clue as to a probable explanation. The nature of the population of children served by SMA has changed dramatically during the time span represented in this table. Some of the factors causing this change (such as the current social trend toward deinstitutionalization) are external to SMA. However, a retrospective examination of the situation would seem to suggest that the existence of the HRC had an effect quite different from initial staff fears. The existence of the HRC appears to have provided SMA administrators and staff with a measure of assurance that external review would occur in an orderly manner and that potentially controversial treatments could be proposed and discussed before they were tried. Such assurance tends to permit the staff to admit children with more severe and diverse problematic behaviors than would otherwise have been the case. The apparent effect of the Human Rights Committee, thus, has been that at least some children who would have had to receve

their educational services in institutional settings are able to attend a public school program.

Table 1

Frequencies of Individual Intervention Programs

	1979/80	1980/81	1981/82	1982/83
severity of behavior:				
life-threatening	3	19	21	21
nonlife-threatening	5	10	39	33
type of consequence used in the program:				
matrest	0	7	17	20
time-out room	3	7	8	4
restraints	0	1	4	9
aversives	0	1	9	7
other restrictive programs	0	2	3	1
non-restrictive programs	5	11	18	13
total number of children in the program	82	90	109	118

[a] as of February 16, 1983

REFERENCE

Turnbull, H.R. and Turnbull, A.P. Free Appropriate Public Education: Law and Implementation. Denver: Love, 1978.

NOTES

1 Paper presented at the 91st annual meetings of the American Psychological Association, August 30, 1983, Anaheim, California. 2 The authors wish to thank Fran Buekelman for her assistance in the preparation of this manuscript.